Catalogue no. 82-003-X
ISSN 1209-1367

Health Reports

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Release date: November 19, 2014

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.	not available for any reference period
..	not available for a specific reference period
...	not applicable
0	true zero or a value rounded to zero
0^s	value rounded to 0 (zero) where there is a meaningful distinction between true zero and the value that was rounded
^{p}	preliminary
^{r}	revised
x	suppressed to meet the confidentiality requirements of the *Statistics Act*
^{E}	use with caution
F	too unreliable to be published
*	significantly different from reference category ($p < 0.05$)

Parkinson's disease: Prevalence, diagnosis and impact

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Abstract
This article provides information on Parkinson's disease, using the 2010/2011 Canadian Community Health Survey, the 2011/2012 Survey of Neurological Conditions in Institutions in Canada, and the 2011 Survey of Living with Neurological Conditions in Canada. An estimated 0.2% of Canadian adults in private households (55,000), and 4.9% of those in residential institutions (12,500) had Parkinson's disease. Younger age at symptom onset was associated with a longer period to disease diagnosis. As a result of the condition, 58% reported that social interactions were negatively affected, 61% reported out-of-pocket expenses, and 56% reported receiving assistance with activities such as housework, transportation or personal care. Among those receiving assistance, 84% relied at least in part on family, friends or neighbours. The primary informal caregiver tended to be a spouse (64%), female (62%), live in the same household (72%), and provide assistance on a daily basis (76%).

Keywords
Caregivers, neurological disease, limitation of activity, self-care

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Parkinson's disease is the second most common neurodegenerative disorder after Alzheimer's disease.[1] It results from the loss of cells in the brain that produce dopamine, a chemical that controls the body's movements. As dopamine decreases, tremors can develop, muscle movements become slower and more rigid, and reflexes become impaired contributing to a loss of balance. Other symptoms may include depression, anxiety, emotional changes, cognitive impairment, difficulty swallowing, chewing and speaking, masked facial expressions, urinary problems, constipation, fatigue, and sleep problems. Parkinson's disease is a chronic, progressive disorder, meaning that symptoms continue and worsen over time. The cause is unknown, and although there is currently no cure, medications and other treatment options are available to manage its symptoms.

This study presents two prevalence estimates of Parkinson's disease. The first is for the population in private households and is based on data from the 2010/2011 Canadian Community Health Survey. The second is for the population in long-term residential care facilities and is based on data from the 2011/2012 Survey of Neurological Conditions in Institutions in Canada (see *The data*). The detailed analyses are based on data from the 2011 Survey of Living with Neurological Conditions in Canada, and pertain to people who lived in private households. The time from symptom onset to diagnosis was estimated for everyone with Parkinson's. The social, financial and physical impacts and the characteristics of caregivers were examined for people with Parkinson's, but not any of the other neurological conditions covered in the survey.

The data

Data source

This study was based on the Neurological Conditions Prevalence File, which was derived from the 2010/2011 Canadian Community Health Survey (CCHS)—Annual Component, the 2011 Survey of Living with Neurological Conditions in Canada (SLNCC), and the 2011/2012 Survey of Neurological Conditions in Institutions in Canada (SNCIC). Detailed documentation for these surveys is available at www.statcan.gc.ca.

The CCHS is a cross-sectional survey that collects health information about people aged 12 or older living in private households. The sampling frame excludes full-time members of the Canadian Forces, residents of reserves and other Aboriginal settlements in the provinces and in some remote areas, and the institutionalized population. The Neurological Conditions module of the CCHS collected information on all household members, thereby increasing sample size and providing data for the population younger than age 12. This yielded a final sample size of 285,971 in the Neurological Conditions Prevalence File. The response rate was 70.6%.

The cross-sectional SLNCC explored issues related to neurological conditions, including diagnosis, medication use, and impact. It targeted Canadians aged 15 or older in private households. In addition to groups excluded from the CCHS, the SLNCC excluded residents of the three territories. The sample consisted of 4,569 respondents. The response rate was 81.6%. Ages of symptom onset and of diagnosis were based on a sample of 356 people with Parkinson's, representing an estimated 47,500 people. Analysis of the impact of Parkinson's was based on a sample of 274 respondents with Parkinson's disease but none of the other neurological conditions covered by the survey; they represented an estimated 35,900 Canadians.

The SNCIC was a census with a cross-sectional design. It collected information about the numbers of people in long-term care facilities who had been diagnosed with selected neurological conditions, including Parkinson's disease. Long-term residential care facilities with four beds or more, and which were approved, funded or licensed by provincial/territorial departments of health and/or social services, were included in the survey.[2] The SNCIC sample consisted of 4,245 institutions. The response rate was 63.5%.

Definitions

Respondents were asked about selected chronic neurological conditions (including Parkinson's disease) that had lasted or were expected to last six months or more and that had been diagnosed by a health professional.

Respondents with neurological conditions were asked four questions about social interactions. Those who responded "always," "often" or "sometimes" versus "rarely" or "never" were considered to have interactions that had been affected by the condition.

Respondents were asked about assistance they received in the past 12 months at home, work or school because of their neurological condition. Types of assistance from formal and informal sources were asked separately, but combined for this analysis.

The caregiver was the family member, friend or neighbour who had dedicated the most time and resources to providing informal assistance in the past 12 months. Spouse caregivers referred to married, common-law, same sex partner and ex-spouse relationships; other family members (including in-laws), friends and neighbours comprised other caregivers. Caregivers were classified as currently working if they had worked at a job or been absent from work in the week before the interview. Respondents reported if their caregiver worked full or part time. The frequency of care from the main caregiver was classified as daily or less than daily.

Weighted frequencies, cross-tabulations and means were used to examine the prevalence of Parkinson's disease and its impact. To account for survey design effects, in this analysis, standard errors and coefficients of variation were estimated using the bootstrap technique.[3,4]

Limitations

Neurological conditions were self-reported by individuals (household) or by proxy respondents (institutions) and not verified by any other source. For people in institutions, only prevalence data were available; therefore, most of the analyses concern the household population and do not represent residents of health care institutions.

CCHS respondents were asked if they, or someone in their household, had been diagnosed with selected neurological conditions. People reported to have a neurological condition were selected to participate in the SLNCC and were again asked about all of the neurological conditions of interest. There were 72 respondents who were reported to have Parkinson's based on the CCHS, but not on the SLNCC. In addition, 17 respondents did not have Parkinson's based on the CCHS, but did on the SLNCC. Details are available elsewhere.[5]

Of those with Parkinson's, 23% had at least one other neurological condition that was included on the survey. The average age of those with Parkinson's only (73.7 years) was not significantly different from that of people with Parkinson's and at least one other neurological condition (72.5 years). SLNCC respondents answered questions about all their neurological conditions, because it would be difficult for people with multiple conditions to isolate the impact of one from that of others. For this study, the social, financial and physical impacts and caregiver characteristics were examined for people with Parkinson's, but none of the other selected neurological conditions. Although this excludes people with more than one condition (thereby yielding what might be a slightly healthier sub-population), the estimates were similar when those with more than one neurological condition were included. The strength of examining only those with Parkinson's is that impacts can be attributed directly to Parkinson's, not to another condition.

Questions about medication use specify "prescribed" medications, which can include non-prescription medications if they were prescribed by a health professional. However, when asked about out-of-pocket expenses, respondents were instructed to report on both prescription and non-prescription medications. Thus, the types of medications may differ when respondents report on "use" versus "expenses."

Prevalence of Parkinson's disease

An estimated 55,000 Canadians aged 18 or older living in private households reported that they had been diagnosed with Parkinson's disease. This represented 0.2% (95% CI: 02%, 0.3%) of the household population, unchanged from the 2000/2001 CCHS prevalence estimate.[6] As well, 12,500 residents of long-term residential care facilities—4.9% (95% CI: 4.8%, 5.0%) reported a Parkinson's diagnosis. Among the household population, 79% with Parkinson's were 65 or older; in institutions, almost everyone (97%) with the condition was 65 or older.

Overall, men were more likely than women to have Parkinson's disease: 0.3% versus 0.2% ($p < 0.05$) for those in private households, and 6.6% versus 4.0% ($p < 0.05$) for residents of institutions.

In general, the prevalence of Parkinson's disease increased with age, although in the institutionalized population, prevalence decreased in the oldest age group (Figures 1 and 2). This may reflect greater disease severity and higher mortality among older people in institutions compared with those in private households.[7] As well, being male and the presence of symptoms such as severe motor impairment, psychosis and dementia have been associated with earlier death among people with Parkinson's.[8]

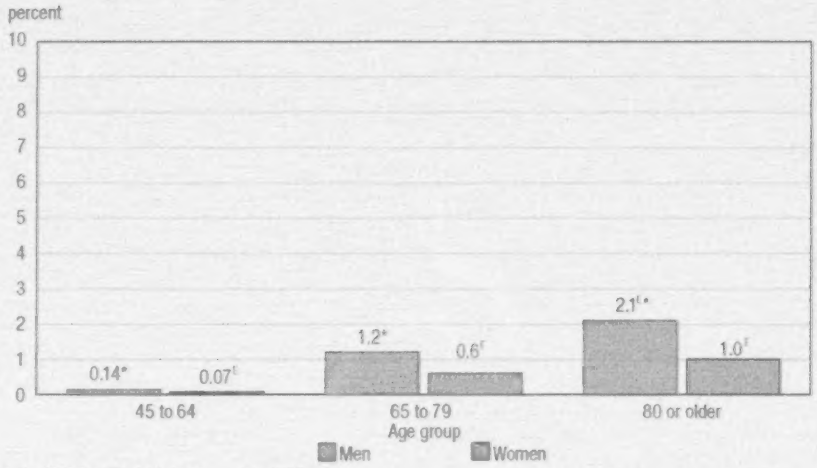
From symptoms to diagnosis

The average age at which people first experienced symptoms was 64.4 years, with a diagnosis of Parkinson's 1.9 years later at 66.2. The period between symptom onset and diagnosis was longer for younger people—an average of almost 7 years (Table 1). Physicians may initially rule out Parkinson's in younger people, since it predominantly affects older adults.[9]

Interactions with others

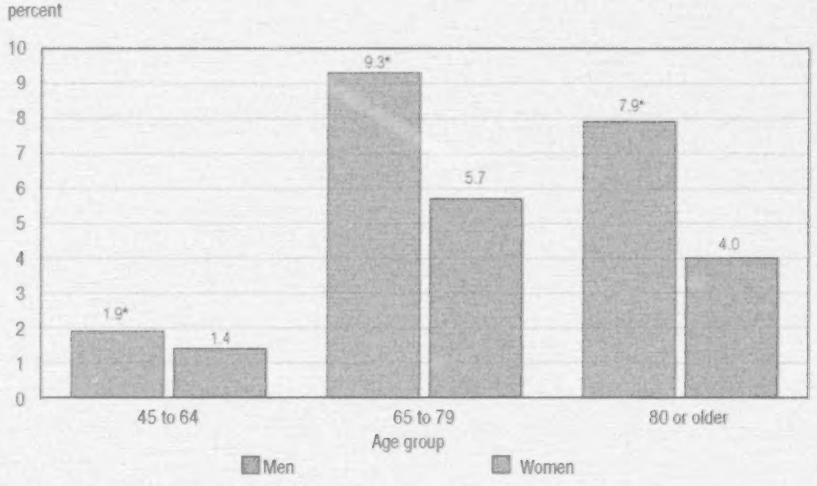
Considerable numbers of people with Parkinson's reported feeling embarrassed by the condition (43%) or left out of things (29%). Some perceived that others were uncomfortable with them (28%) or avoided them (19%). More than half (58%) reported that they had at least one of these concerns (Figure 3).

Figure 1
Prevalence of Parkinson's disease in household population, by age group and sex, population aged 45 or older, Canada excluding territories, 2010/2011



* significantly different from women ($p < 0.05$)
E use with caution
Source: 2010/2011 Canadian Community Health Survey — Neurological Prevalence File.

Figure 2
Prevalence of Parkinson's disease in institutional population, by age group and sex, population aged 45 or older, Canada excluding territories, 2011/2012



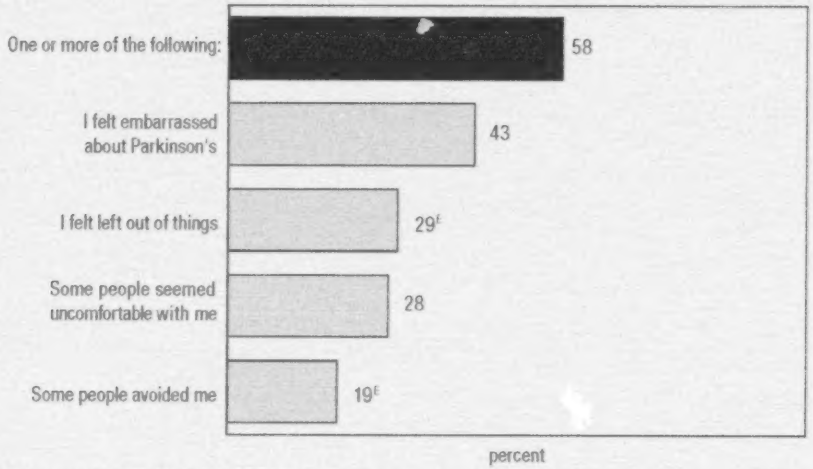
* significantly different from women ($p < 0.05$)
Source: Statistics Canada, CANSIM Table 105-1305.

Table 1
Mean age at symptom onset and diagnosis of Parkinson's disease, by age group at symptom onset, household population aged 18 or older, Canada excluding territories, 2011

	Age group at symptom onset			
	Younger than 50	50 to 64	65 to 79	80 or older
Mean age at diagnosis	50.7**	59.4**	71.4**	83.6
Mean age at symptom onset	43.8	57.4	70.5	83.5
Mean years between symptom onset and diagnosis	6.9*	2.0*	0.9*	0.1*

** significantly different from mean age of symptom onset ($p < 0.01$)
* signficantly different from other age groups ($p < 0.05$)
Source: 2011 Survey of Living with Neurological Conditions in Canada.

Figure 3
Percentage with Parkinson's disease[†] whose interactions with others affected[‡] by condition, household population aged 18 or older, Canada excluding territories, 2011



[†] no other selected neurological conditions
[‡] "sometimes," "often" or "always" versus "rarely" or "never"
[E] use with caution
Source: 2011 Survey of Living with Neurological Conditions in Canada.

Table 2
Characteristics of caregivers of people with Parkinson's disease,[†] household population, Canada excluding territories, 2011

Caregiver characteristics	%	95% confidence interval from	to
Sex			
Male	38.1[E]	24.0	54.6
Female	61.9	45.4	76.0
Lives in same household	72.2	55.8	84.2
Relationship to care receiver			
Spouse[‡]	63.8	48.9	76.5
Other (family, friend, neighbour)	36.2[E]	23.5	51.2
Frequency of care			
Daily	75.7	59.2	87.0
Less than daily	24.3[E]	13.0	40.8
Employment status			
Full-time	23.2[E]	12.4	39.2
Part-time	13.7[E]	7.1	24.8
Not employed	63.1	48.4	75.7

[†] no other selected neurological conditions
[‡] married, common-law, same sex partner, ex-spouse
[E] interpret with caution
Source: 2011 Survey of Living with Neurological Conditions in Canada.

Out-of-pocket expenses

Almost two-thirds (61%) of people with Parkinson's reported out-of-pocket expenses during the past 12 months as a result of the condition—expenses that would not be reimbursed by insurance or government programs. Most people with Parkinson's took prescribed medication for the condition (94%), but just 47% of them reported that they incurred out-of-pocket expenses for their medications (prescribed or over the counter) (Figure 4). It is possible that they did not count or remember expenses such as dispensing fees, insurance deductibles, or the costs of non-prescription medications. Close to half (46%) of those who reported out-of-pocket medication expenses in the past 12 months indicated that these amounted to $500 or more.

In addition to medications, substantial percentages of people with Parkinson's disease incurred out-of-pocket expenses for assistive devices (23%) such as mobility and agility aids, rehabilitation therapy (18%) such as physical and speech therapy, and home care (15%) including health care, homemaker and other support services. Almost half (45%) of those with out-of-pocket expenses for assistive devices or rehabilitation therapy reported that these expenses amounted to $500 or more in the past 12 months. And although just 15% reported expenses for home care, 67% of this group spent at least $500.

Assistance

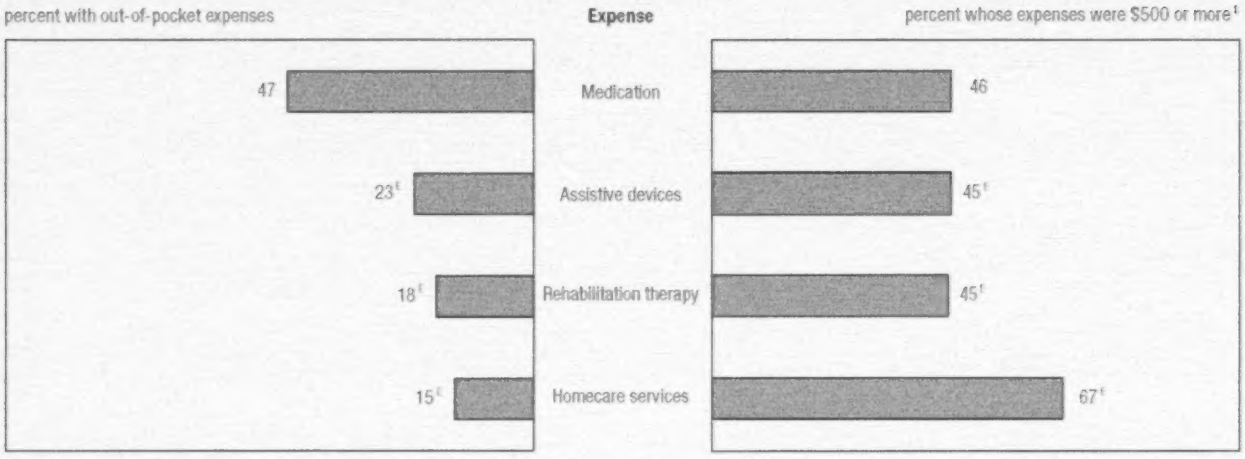
In the previous 12 months, 56% of people with Parkinson's disease received formal and/or informal assistance at home, work, or school because of their condition. The types of assistance most frequently reported were help with activities such as housework, home maintenance or outdoor work (80%); emotional support (77%); transportation including trips to the doctor or for shopping (70%); and meal preparation or delivery (64%). Fewer needed assistance with personal care such as eating, dressing, bathing or toileting (57%); making appointments or managing personal finances (53%); or medical care such as taking medicine or nursing care (39%). Previous research has shown that seniors who need assistance with personal care are more likely to live in institutions.[10]

Caregivers

Among those who received assistance because of Parkinson's disease, 84% relied at least in part on family, friends or neighbours. Referred to as "informal" assistance, or caregiving, this is distinguished from "formal" assistance provided by organizations with paid or volunteer workers. Sources of assistance may be influenced by the availability of caregivers and volunteer and paid services, as well as financial resources. More than half (56%) relied solely on informal assistance.

The main caregiver was typically a woman (62%), lived in the same household (72%), and provided assistance on a daily basis (76%) (Table 2). For the most part, the recipient's spouse was the main caregiver (64%). On average, spouse caregivers were aged 69; 22% were employed at a job or business. Main caregivers who were other family members,

Figure 4
Prevalence of out-of-pocket expenses in past 12 months because of Parkinson's disease,† household population aged 18 or older, Canada excluding territories, 2011



† no other selected neurological conditions
‡ among those who reported out-of-pocket expenses
E use with caution
Source: 2011 Survey of Living with Neurological Conditions in Canada.

friends or neighbours were younger—52, on average ($p < 0.05$); 66% of them were employed full or part time.

Conclusion

This study highlights the prevalence and impact of Parkinson's disease in Canada. An estimated 0.2% of adults in private households and 4.9% of those in residential care facilities had the condition. Younger age of symptom onset was associated with a longer period to disease diagnosis. More than half of people with Parkinson's reported that it negatively affected their social interactions, and almost two-thirds reported out-of-pocket expenses as a result of the condition. Spouses were the primary caregiver for the majority of people with Parkinson's. Most caregivers provided assistance on a daily basis.

Acknowledgements

Statistics Canada thanks all participants for their input and advice during the development of the neurological content for the Canadian Community Health Survey, the Survey on Living with Neurological Conditions in Canada, and the Survey of Neurological Conditions in Institutions in Canada. The content of these surveys was developed jointly by the Health Statistics Division at Statistics Canada and the Public Health Agency of Canada (PHAC), with input from PHAC's expert advisory group members who specialize in the study of neurological conditions. Content was selected based on objectives and data requirements specified by PHAC. Sponsorship was provided by PHAC as part of the National Population Health Study of Neurological Conditions.

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